

Bismarck Session – Comments From Participants

- **Attitude**
 - The attitude of the Human Service workers needs to be better and more open to helping the parents and families of the child
 - NDHS should have support groups to hear the voices of the parents and understand what the parents and families are going through
 - Case Managers need to have a better attitude and be more informed
- **Legislative Action**
 - More aggressiveness in legislature for additional funds
 - They need to hear the parents and make a difference
 - They need to be more informed about the issues that are affecting the families of a child with a special need
- **Hoops to go through**
 - Parents feel as if there are so many hoops they have to jump through to get anything for their child
- **Justify everything**
 - Parents feel that everything has to be justified
 - They have many questions why some things do and some don't
 - Would like to know what Medicaid covers
 - MRDD qualifications are unclear
- **No one there to help**
 - Feel very alone and don't know where to go for help and comfort
- **Hitting a brick wall**
 - Feel as if they can go so far and then hit a wall and don't know where to go from there
 - All they try and change just does not get taken care of
- **Does anyone listen or care**
 - Can only talk so much with pediatrician, then do not know whom else to console with
- **Support groups**
 - Need some kind of network to share with others feelings about their child and know that there are others out there with the same thoughts
 - Need to be able to voice their opinions to others
- **Lack of awareness**
 - Parents do not feel informed about support and information that could benefit their children
 - Need a solid and reliable source of information

Children's Health Focus Group Notes – Bismarck

I. Methods of awareness

Bismarck

St. A's Pediatric department
St. A's Respiratory Therapist
Letter from school
Early intervention program
Family voices – 2 people
Telemedicine Coordinator

Ashley

Telemedicine Coordinator

Dickinson

Family Voices

II. Accessing information about Programs/Services

A. Bismarck

Word of mouth, other parents, teachers, the Magic foundation, SSI, hard to find people to talk to, no one tells us, from sister, you're given the run-around, you have to talk to a lot of people, pattern in which they give info. is ineffective, fed up with the state, state doesn't want us to bother them (legislators), inquiry not welcomed, I've had to initiate everything by talking to networks, lack of awareness

Early intervention from birth-3 years old – there is a lot of information.
After 3, little info. sent through IEP, not a good clearinghouse for info. It is screened – they don't give us all the info.

I feel alone – the problem solving isn't there
I have a lot of resources but I still feel alone

Doctors don't know what my daughter has – very frustrating
Not enough information and knowledge from the doctors to give general information to us families

B. Dickinson

IAP teacher in school
Network with organizations around the state

C. Ashley

Had to initiate oneself

III. Accessing Information – Additional comments

Depends if NDHS wants to tell us
Case Managers need to be more informed
5 out of 8 in Bismarck have Case Managers
2 out of 2 in Dickinson have Case Managers
0 out of 1 in Ashley have Case Managers
Case Managers need to be more proactive and knowledgeable
North Dakota is lacking in care and needs for children
Knowledge – in ND there is not enough knowledge about my daughter's problem
Doctors don't know what to do – stuck with school system and social services and they don't see anything wrong with her
Hard to get 2nd opinion in ND – difficult to get approval to get an out-of-state opinion
Medicaid won't cover past age 3
Medicaid and SSI see it as parents are getting ND money and trying to live off the system
Medicaid and SSI have different financial criteria - inconsistent
One mom confined to stay at home or child would lose medical coverage and they don't qualify for other assistance
Can't take stock option at work because there are too many assets – we can't save – we will have to work the rest of our lives – haven't worked for 11 years

IV. Working with Health Care Professionals

A. Bismarck

Trying to get on Medicaid is a nightmare
No main entity for care of child
Respiratory care should not be up to the parents, it should be up to agencies like Easter Seals – parents cannot handle that kind of pressure
Easter Seals is a good program, but it comes back to the State wanting to do it
Cutting back of funds hurts
Need support for the families and siblings to understand what is going on
Need fun activities for their child – they need it for mental health – make it a family affair
Children and families need better information about what is wrong and needs to be done
Need quality care to come in and support our children
I have an excellent system but they don't always have a qualified staff
I deal with school districts – I am in a different situation
Social service agencies need to step up and coordinate care
I deal with school districts and a psychologist– I am in a different situation
Funding for Human Services should be for Human Services and not turned back at the end of the year
Dept. of Developmental Disabilities sets families up, but then lets the family go
Need more aggressiveness in the legislature for additional funds
We have so much reliance on medical money, but the legislature is restricted
You shouldn't have to beg them for help

B. Dickinson

We have an excellent system, but we do not always have a qualified staff

C. Ashley

I deal with school districts and psychologists

Social service agencies need to step it up and coordinate care

V. Access to Needed Services

A. Bismarck

Make the programs you already have work for the families and the child

Attitude needs to change – they don't trust you

They make you feel like you're not worth anything medical, respite, etc.

MR services – many people don't qualify

We don't use telecommunications enough – we need to use technology

B. Dickinson

Need adequate mental health care – you can't afford it and you don't have a choice of Doctors

C. Ashley

No specialists close by – need to travel 3 hours to get specialized care

VI. Miscellaneous

A. Bismarck

CSHS use to be named Crippled Children's Services

Epilepsy is not covered

2 of 8 in Bismarck have heard of Children Special Health Services

0 of 1 in Ashley had heard of Children Special Health Services

2 of 2 in Dickinson had heard of Children Special Health Services

CSHS should be there to answer our questions

CSHS should be a resource for information

Nothing ever gets accomplished

One hour is not enough to hear our opinions

Someone from Human Services should be here to listen – people who vote these issues need to be here and need to know about us

In an article in Tribune "Desperate Measures" - couple shouldn't have to get a divorce to get medical help for a child

Can't take my child to a daycare once they turn 12 – you end up relying on older siblings for help babysitting and you can't expect them to do that

Care providers need to be more aware of what is available for daycare needs

My daughter can't go to daycare because she can't be around the public and risk the chance of getting sick

Siblings of special children need to have knowledge

We are always blazing trails

The attitude isn't "How can I help you?" but "What are you going to do?"
We're all a priority – every kid is important – every need is unique and NDHS needs to be more open with all cases and providing care
The state doesn't understand that we're in this situation by chance – we didn't ask for it and we need their support
The state will have to be more involved – cost of care keeps going up
The whole legislative process needs to be educated
Protection & Advocacy has a group that meets to rise issues in the legislature for children with special care needs – they meet monthly

B. Dickinson

Family-to-family network located in Grand Forks
-this is a way to network families that have children with the same type of special needs
Family Voices is very good

VII. Closing Comments

We feel like nothing is getting accomplished – we have these meetings and nothing changes
It's too much for the families
NDHS needs to have meeting more often to hear the voices of parents and to understand what parents are going through and then provide follow-up

Many things are kept a secret from parents – case managers don't tell

You keep hitting a wall – you get excited thinking you're going to change things and then nothing happens

Have to get pre-authorization
-inconsistency in whether you have to get it or not
MDA people assume MDA will cover everything, but they don't
We need to know what Medicaid covers
Parents need to know of where to go
MRDD qualifications are unclear
Need a comprehensive health care plan for special care children
CSHS won't pay for everything

All this doesn't make sense to the families of how they care for the children up to 3 years old and then drop them and leave the care up to the families

****Please tell us the results from this meeting! We are willing to be at other meetings!****

Notes from parent who attended the focus group session – called Mike after meeting and visited for 30 minutes.

- daughter has muscular dystrophy
- something should be put together in a binder in a simple understandable language for parents to understand what is covered and what is not
- give to each person on medical assistance
- when things occur, send out to replace in their binder
- haven't worked for 11 years – I have no future!
- parents need to be informed of changes
- article “Desperate Measures” series that ran the Tribune in April – needs to be sent to Conrad and Dorgan
- a small group needs to get legislators, House, Senate and Congress to hear the needs

- SSI - \$500/month – recipient liability a problem
- hard to send SSI – must check back after getting “Make a wish”
- they watch them like a hawk – focus on disqualifying them

- many jobs aren't flexible for families with kids with special needs

- all they care about is getting best possible care

- can't put more pressure on families
- need support for other kids

- they make you feel like you are nothing
- we are fighting for everything
- do they really care?
- Life is all very complicated

- MD & MS's not enough education out there
- people want to be self-sufficient